

HB4088A Amendment Request: Protect Health Researcher Access to Critical Data

Introduction

HB4088A takes important steps to improve the privacy of patients and physicians relating to reproductive or gender-affirming health care – but inadvertently restricts access by researchers and the general public to critical public health information about these health care activities. In doing so, the bill may actually harm patients seeking this care.

Please amend HB4088 to ensure critical access to this important real world data.

Section 3 prevents even “private citizens” from accessing information about reproductive and gender-affirming health care activities

Problem:

- The section caption (title) has no legal weight – so this isn’t just about “federal and interstate investigations” – it is about ANY “inquiry into a reproductive or gender-affirming health care activity” by anyone, even “a private citizen” in Oregon.
- This could prevent public health researchers, the news media – or even prospective patients – from accessing information about “prenatal, postnatal and delivery care,” “treatments for sexually transmitted infections,” or “any other health care and medical services related to reproductive health” – not just gender affirming treatment or pregnancy termination.

Proposed Amendment:

On page 2, line 24, delete “, a private citizen” and “an investigation or”.

In line 25, delete “inquiry” and insert “a federal or interstate investigation”.

(2)(a) Except as provided in ORS 24.500 and 133.747, or as required by federal law, an officer, employee or agent of a public body may not cooperate with, provide information to or otherwise expend or use time, moneys, facilities, property, equipment, personnel or other resources to assist a federal law enforcement agency, a law enforcement agency of another state, ~~a private citizen~~ or a quasi-law enforcement agent in relation to ~~an investigation or inquiry~~ a federal or interstate investigation into a legally-protected reproductive or gender-affirming health care activity, if such activity would be lawful if it occurred entirely in this state.

**Section 9 would block public health researchers from using APAC
“Limited Data Sets” in a manner consistent with Oregon and Federal law**

Problem:

- Individually identifiable health information must be guarded very carefully – and is already thoroughly protected by state and federal law
- However, Oregon and Federal law [e.g., ORS 442.373 and 45 C.F.R. § 164.514(e)] do allow limited release of protected health information to researchers – as long as all “direct identifiers” (like names, addresses, social security numbers) are removed. Researchers must follow strict contractual controls, in close coordination with the Oregon Health Authority. [See <https://www.law.cornell.edu/cfr/text/45/164.514>]
- Oregon’s “All Payer All Claims Reporting Program” provides this data to public health researchers under a carefully controlled program that is highly effective at preventing misuse. This “real world data” is critical to developing new medicines, improving medical technology, and identifying or resolving concerns about potential risks and side effects. [See <https://www.oregon.gov/oha/hpa/analytics/pages/all-payer-all-claims.aspx>]
- Section 9 prevents public health researchers from accessing this critical “real world data” – for any topic relating to “reproductive and gender-affirming health care.”

Proposed Amendment:

- This text is taken directly from Federal HIPAA regulations in 45 C.F.R. § 164.514(e)(2) “Implementation specification: Limited data set”

On page 4, after line 40, insert:

“(3) Nothing in this section prohibits the authority from including data derived from information related to a legally protected reproductive or gender-affirming health care activity in the limited use data sets included in the comprehensive health care information system developed under ORS 442.373, provided the following direct identifiers of the individual or of relatives, employers or household members of the individual are excluded:

“(a) Names;

“(b) Postal address information, other than town or city, state and zip code;

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- “(c) Telephone numbers;**
- “(d) Facsimile numbers;**
- “(e) Email addresses;**
- “(f) Social Security numbers;**
- “(g) Medical record numbers;**
- “(h) Health plan beneficiary numbers;**
- “(i) Account numbers;**
- “(j) Certificate or license numbers;**
- “(k) Vehicle identifiers and serial numbers, including license plate numbers;**
- “(L) Device identifiers and serial numbers;**
- “(m) Internet universal resource locators;**
- “(n) Internet Protocol address numbers;**
- “(o) Biometric identifiers, including finger and voice prints; and**
- “(p) Full face photographic images and any comparable images.**